

Understanding the pathway between the transplant experience and health-related quality of life outcomes in adolescents

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Abstract: Developments in solid organ transplantation have resulted in improved survival for children with advanced kidney, liver, and heart disease; however, concerns have been raised regarding the quality of life of survivors. This study examined HRQOL in adolescent transplant recipients. We examined the influence of demographic, treatment regimen, and family factors on physical and mental health domains of HRQOL. The current single-center investigation involved 68 solid organ transplant recipients and their parents. All families participated in a structured interview to collect information on demographics, characteristics of the adolescents' disease and treatment regimen, family functioning, and HRQOL for parents and adolescents. Using hierarchical regression analyses, predictive models of physical functioning and mental health outcomes for adolescent transplant recipients were developed for parent-proxy and adolescent self-report. Perceived frequency of medication side-effects and family conflict significantly contributed to adolescent physical functioning and mental health outcomes. Taken together, transplant consequences and family environment significantly impact physical and mental health outcomes in adolescent transplant recipients. Our findings demonstrate the need for pharmacological considerations and psychological interventions to address these areas.

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Survival rates for pediatric kidney, liver, and heart transplant patients have increased over the past 20 yr (1), with three-yr organ survival rates ranging from 67% to 89% for adolescent transplant recipients (2). Although overall functioning is dramatically improved following transplantation, living with a transplanted organ can result in adverse physical and emotional consequences and limitations on physical and social activities (3, 4). As a result, adolescent transplant recipi-

ents have a lower HRQOL than their healthy peers (5). HRQOL is a multifaceted construct that has been defined as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (6). Only a limited range of factors that influence HRQOL in pediatric transplant patients have been studied thus far. For example, in a study assessing pediatric liver transplant patients, physical and psychosocial HRQOL was not significantly associated with age, time since transplant, type of graft, or medical history (e.g., prior complicated infections, hospital days in past six months) (7).

Although research on HRQOL in pediatric transplant patients is scarce, several studies have examined the relationships between related constructs and potential risk factors or predictors.

Abbreviations: CHQ-50, Child Health Questionnaire-Parent Form 50; CHQ-87, Child Form 87; ESRD-SCL, End-Stage Renal Disease Symptom Checklist-Transplant Module; HRQOL, health-related quality of life; *M*, mean; MAM, Medical Adherence Measure; s.d., standard deviation.

For example, in terms of demographic factors, research has found that younger transplant patients and patients whose parents were unemployed report higher rates of anxiety (8). Also, male patients reported significantly lower global self-worth than their female counterparts, specifically in the domain of perceived athletic competence (9). These gender differences were greater in participants 13 yr of age and older. Also, when compared with healthy peers, female transplant recipients reported comparable global self-worth, but perceived themselves as performing lower scholastically and behaviorally (9). Disease characteristics have also been shown to influence patients' functioning. Physical symptoms and limitations associated with transplantation have been associated with more depression and anxiety and lower self-esteem (3, 10, 11). Physical limitations and pain may preclude participation in social and athletic activities, thus interfering with the development of peer relationships (4). In addition, the intensity of side-effects has been associated with medication non-adherence in pediatric transplant patients, with female transplant recipients often citing cosmetic side-effects (e.g., acne, facial swelling, and weight gain) as the reason for non-compliance (12). Understanding the influence of medication side-effects on self-esteem and self-worth, may provide insights into how side-effects influence non-adherence. In addition to demographic and disease factors, family dynamics also influence patient functioning. A three-yr study found that pediatric heart transplant patients' levels of depression and anxiety were negatively correlated with caregiver support (13).

Although research on factors associated with emotional adjustment in pediatric transplant patients are increasing, studies examining predictors of perceived physical and mental health outcomes are still limited in number and scope. This study expands prior investigations in this area in several important ways. First, this investigation includes kidney, liver, and heart transplant patients; thus increasing understanding of physical and mental health outcomes across organ groups. Second, HRQOL, as measured by the Child Health Questionnaire, was assessed using parent and adolescent reports, allowing for a more thorough understanding of this multi-faceted construct. Third, this study examined various demographic, medical, and family factors that may contribute to adolescent physical and mental health outcomes. Understanding factors that influence physical and mental health outcomes for pedi-

atric transplant recipients may ultimately help in the design and implementation of therapeutic interventions (14).

With regards to our hypotheses, for demographic variables we hypothesized that younger age and low socioeconomic level would be associated with lower mental health scores on the CHQ, as found in previous studies. No specific relationships between demographic factors and physical functioning were predicted. We hypothesized that less time since transplant, a greater number of medications, less medication knowledge, and more frequent side-effects would predict lower physical and mental health scores on the CHQ. For family variables, we hypothesized that greater family conflict and poor parental quality of life would predict lower physical and mental health scores on the CHQ for pediatric transplant recipients.

Method

Participants

The current study included 68 adolescent transplant recipients (44% female, 56% male) aged 11–20.7 ($M = 15.8$, $s.d. = 2.5$). Thirty-nine kidney transplant recipients, 17 liver transplant recipients, and 12 heart transplant recipients made up this group. Among the liver and kidney patients, 20 received their organ from a living donor. Time since transplant ranged from four months to 15.4 yr ($M = 4.8$, $s.d. = 4.4$). The majority of the sample was Caucasian (65%), with the remaining sample African American (27%) and other (8%). Most of the parents in this sample were married (62%). The median family income ranged from 25 000 to 50 000 dollars/yr. To be included in this study participants had to have a solid organ transplant, be at least 11 yr old, currently living at home with their parent(s), English speaking, and have both the parent and adolescent participate in the interview. Exclusion criteria included being diagnosed with a developmental delay or having a psychotic disorder. Ninety-two percent of the approached families participated. Non-participants included three who declined based on lack of time, one who did not wish to release medical records, and three who did not provide a reason.

Overview of measures

The measures collected in this study were part of larger investigation examining health behaviors in adolescent transplant recipients (15). Phone interviews were completed individually with each parent and adolescent. They answered questions about adolescent HRQOL, family conflict, medication knowledge, and perceived medication side-effects. Parents also reported on their own quality of life. The prescribed medical regimen and patient history data were obtained through medical record review.

Medical record review

The principal investigator and trained research assistants conducted an electronic medical record review at the hospital, collecting data on transplant type, donor type for

kidney and liver patients (living vs. deceased), time since transplant, and current medication regimen.

Adolescents' medication knowledge

Adolescents' medication knowledge was assessed based on the MAM (16). This measure assesses: (i) the name of each medication, (ii) dosage frequency, (iii) dosage amount, and (iv) medication purpose. Responses were then compared with the current medication regimen in the medical chart, with a possible total score of four for each medication. Internal consistency estimates were excellent for these items in this sample ($\alpha = 0.84$). This total was then divided by the number of medications and multiplied by 100, with a higher percentage signifying greater medication knowledge.

Adolescents' perceptions of side-effects

The ESRD-SCL (17), validated for use with adults, was adapted for use with this sample. The adapted scale measures the frequency of 39 different side-effects (e.g., weight gain, bruising) on 5-point Likert-like scales. The scales range from *never* to *always*. Adequate construct validity and internal consistency have been demonstrated for the ESRD-SCL. Total frequency scores were derived by totaling the frequency ratings. The internal consistency estimates for frequency of side-effects in this sample was excellent ($\alpha = 0.91$).

Family conflict

The conflict subscale of the Family Environment Scale was used (18). This is a nine-item scale in which respondents endorse "yes" or "no" for each item. Prior research comparing normal and distressed families found higher conflict scores for distressed families (18). The internal consistency for this scale in this sample is acceptable, 0.86.

Adolescent health-related quality of life

The CHQ-50 (19) and CHQ-87 (19) consist of 50 and 87 items, respectively, that assess the adolescents' HRQOL. Both measures examine the physical and psychosocial well-being of children five yr of age and older. For this investigation we examined the following eight subscales: Physical Functioning, Pain, General Health Perceptions, Mental Health, Self-Esteem, Behavior, Family Activities, and Family Cohesion. Each item on these scales includes a 4–6 point Likert scale. Subscale scores are derived by transforming the sum of each individual item. Scores for each subscale range from 0 to 100, with higher scores representing better functioning. The CHQ-50 and CHQ-87 have been used extensively and have well established reliability and validity for several chronic illness populations, such as juvenile rheumatoid arthritis, epilepsy, asthma (19) and pediatric transplant (20).

Parent health-related quality of life

The SF-12 (21) Health Survey is a measure of adult physical and emotional health domains. This psychometrically sound, 12-item measure is a shortened form of the SF-36 Health Survey (22). The SF-12 consists of eight subscales. The physical functioning, mental health, and social functioning scales were used in this study to measure similar constructs as adolescent physical and mental health functioning, and include a measure of potential social limitations due to parenting a chronically ill child. Scores on each of these three scales can range from 0 to 100, with higher scores indicating better functioning.

Procedure

Recruitment began following Human Subjects approval by the Institutional Review Board. Potential participants were contacted by the transplant coordinator at clinic or via telephone and given a brief description of the study. Participants interested in the study contacted the principle researcher directly, completed an interest form, or consented verbally. Participants were then approached and given a detailed description of the study. Written informed consent and assent were obtained at the clinic or via mail.

Interviews were conducted via phone. Each scale was administered verbally by trained research assistants. The parent and adolescent interviews were conducted separately, with each instructed to leave the room during the other individual's interview. Parent interviews ranged from 28 to 144 min ($M = 55.7$, $s.d. = 15.1$) and adolescent interviews ranged from 24 to 66 min ($M = 42.3$, $s.d. = 8.2$). Interviewers were trained to be sensitive to the parents and adolescents, build rapport with the interviewees, ask interview questions in a clear voice, respond to participant questions without biasing the research, and to do so in a culturally sensitive manner. Data were collected over a five-month period. Twenty dollar gift cards to a local discount department store were given to participants.

Statistics

Data were analyzed with parametric tests using SPSS 14.0 for Windows. Descriptive statistics were conducted for all variables of interest. All variable distributions were examined and significantly skewed variables were log transformed (parent self-reported physical functioning, adolescent reported physical functioning). Paired-sample *t*-tests compared responses between adolescent and parent reports on the overlapping domains assessed by the CHQ. The correlations between parents' and adolescents' reports for the different domains were assessed using Pearson Product Moment correlation analyses. For the analyses examining factors associated with the physical functioning and mental health subscales, one-way ANOVA analyses were conducted with categorical variables (e.g., race, gender, transplant type) and Pearson Product Moment Correlation analyses were conducted with continuous variables (e.g., frequency of side-effects). Lastly, hierarchical regressions were conducted to generate parsimonious models for predicting adolescent physical functioning and mental health scores on the CHQ from the parent and adolescent perspective. Only statistically significant categorical and continuous variables were entered into the regression analyses. Order of step entry was: (i) demographics, (ii) disease and regimen, (iii) family functioning, and (iv) parent health-related quality of life. Family and parent variables were entered last to examine their contribution to adolescent physical and mental health scores on the CHQ beyond the effects of demographic and medical factors.

Results

Comparing parent and adolescent reports on the CHQ

In comparing parent and adolescent responses to physical and psychosocial domains of functioning in the adolescent, two significant differences emerged. As indicated in Table 1, adolescents' general health perceptions were significantly

Table 1. Comparing parent and adolescent reports on the child health questionnaire

Scale	Parent	Adolescent	r	t
Physical				
Physical functioning	88.6 ± 19.0	91.8 ± 12.4	0.27**	1.31
Pain	76.8 ± 27.6	79.7 ± 24.9	0.47**	0.89
General health perceptions	50.3 ± 15.4	59.0 ± 13.2	0.35**	4.36**
Psychosocial				
Mental health	75.2 ± 15.4	75.5 ± 14.5	0.32**	0.14
Self-esteem	74.5 ± 15.4	80.7 ± 15.4	0.41**	2.79**
Behavior	74.6 ± 14.8	78.2 ± 14.5	0.35**	1.78
Family activities	80.1 ± 22.2	79.5 ± 17.8	0.43**	-0.23
Family cohesion	78.5 ± 21.7	73.2 ± 26.2	0.12	-1.37

Values are expressed as mean ± s.d.
 *p < 0.05, **p < 0.01. The correlation between parents' and adolescents' reports is indicated by the r. Differences between the two reporters' scores are indicated by the t.

better than the parental perceptions of their child's health. In addition, adolescents' self-reports were significantly higher than parents' reports of the adolescents' self-esteem. Except for family cohesion, parent and adolescent reports of each of the domains of physical and psychosocial functioning on the CHQ were significantly correlated, with correlations ranging from r = 0.27 to 0.47.

Demographic, medical, and family factors associated with physical and mental health scores

The outcomes of physical functioning and mental health subscales from the CHQ-50 and CHQ-87 were used in these analyses. For categorical demographic and medical variables, no differences were found for age, gender, family income, parent marital status (married vs. other), and organ type for parent and adolescent reports of adolescent physical and mental health. Of note, there was a trend for parents of liver patients (M = 98.0, s.d. = 4.4) to report better physical functioning compared to heart (M = 85.6, s.d. = 15.8) and kidney (M = 85.5, s.d. = 22.5) patients, F (2,65) = 2.93, p = 0.061 (see Table 2 for organ group comparisons). For race, parents of non-white adolescents reported significantly better adolescent mental health (M = 81.7, s.d. = 16.5) when compared with their Caucasian counterparts (M = 71.6, s.d. = 13.6), F (1,66) = 7.26, p < 0.01. For donor status among kidney and liver patients, parents of living donor recipients reported significantly worse adolescent mental health (M = 67.3, s.d. = 11.8) when compared with parents of deceased donor recipients (M = 79.2, s.d. = 15.0), F (1,54) = 9.44, p < 0.01. Child race and donor status were

Table 2. Health-related quality of life (HRQOL) across organ groups

	Heart (n = 12)	Liver (n = 17)	Kidney	ANOVA (F) (n = 3)
Parent reported HRQOL				
Physical functioning	85.6 ± 15.8	98.0 ± 4.4	85.5 ± 22.5	2.93
Mental health	76.4 ± 17.9	78.2 ± 15.4	73.5 ± 14.7	0.55
Adolescent reported HRQOL				
Physical functioning	87.7 ± 13.0	93.5 ± 12.2	92.3 ± 12.4	0.43
Mental health	74.5 ± 19.0	72.3 ± 14.3	77.1 ± 13.1	0.51

Values are expressed as mean ± s.d.
 *p < 0.05

included in the subsequent parent predictive models of adolescent mental health.

For all continuous medical and family variables, the bivariate relationships between predictor and outcome are detailed in Table 3. For parent reported adolescent physical functioning, better adolescent medication knowledge was associated with better physical functioning (r = 0.24, p < 0.05). No other relationships were statistically significant. Adolescent reports of their own physical health were significantly associated with several variables, encompassing medical and family factors. Fewer side-effects (r = -0.50, p < 0.01), less familial conflict (r = -0.25, p < 0.05), and better parent physical functioning (r = 0.28, p < 0.05) were all associated with better adolescent physical functioning reports.

For adolescent mental health outcomes, more frequent side-effects were associated with poorer parent reported adolescent mental health (r = -0.33, p < 0.01). No other continuous medical or familial variables were associated with parent reports of this construct. From the adolescent perspective, more frequent side-effects (r = -0.59, p < 0.01) and greater familial conflict (r = -0.34, p < 0.01) were associated with worse mental health outcomes.

Table 3. Correlates of chq physical functioning and mental health outcomes in adolescent transplant recipients

	Physical functioning		Mental health	
	Parent report	Adolescent report	Parent report	Adolescent report
Medical regimen				
Time since transplant	0.21	-0.03	0.01	0.01
Med knowledge	0.24*	0.15	0.16	0.07
Freq of side-effects	-0.22	-0.50**	-0.33*	-0.59**
Family functioning				
Conflict	-0.07	-0.25*	-0.21	-0.34**
Parent health-related QOL				
SF-12 physical functioning	0.12	0.28*	0.02	0.23
SF-12 mental health	-0.01	0.17	0.17	0.21
SF-12 social functioning	-0.07	0.16	0.07	0.17

*p < 0.05, **p < 0.01.

Table 4. Prediction of adolescent physical and mental health outcomes

Predictor variable	β	r^2	Change in r^2	F
<i>Physical functioning – adolescent report</i>				
Step 1: disease and regimen				
Frequency of side-effects	-0.43**	0.25	0.25**	21.36**
Step 2: family functioning				
Conflict	-0.15	0.27	0.02	12.00**
Step 3: parent health-related quality of life				
Physical functioning	0.19	0.31	0.04	9.36**
<i>Mental health – parent report</i>				
Step 1: demographics				
Child's race [†]	-0.27*	0.13	0.13**	8.09**
Step 2: disease and regimen				
Donor status [†]	-0.24*	0.27	0.14**	6.51**
Frequency of side-effects	-0.27**			
<i>Mental health – adolescent report</i>				
Step 1: disease and regimen				
Frequency of side-effects	-0.55**	0.35	0.35**	35.62**
Step 2: family functioning				
Conflict	-0.23*	0.40	0.05*	21.93**

[†]Child's race (1 = Caucasian, 0 = non-white) and donor status (1 = living donor, 0 = deceased donor) were dummy coded.
For significance level, *p < 0.05, **p < 0.01.

Hierarchical regression analyses to predict adolescent physical and mental health outcomes

As shown in Table 4, three regression models were developed to predict parent and adolescent reports of adolescent physical and mental health. We did not construct a regression model for parent perceived adolescent physical health as adolescent medication knowledge was the only predictor across demographic, medical, and familial variables that was associated with this outcome. For adolescent reported physical functioning, 31% of the variance was accounted for by side-effects, family functioning, and parent self-reported physical functioning. In the final model, fewer medication side-effects emerged as the significant predictor of better adolescent reported physical functioning. Parent HRQOL factors added a 4% increment to the prediction of adolescents' physical functioning.

For parent reported adolescent mental health, 27% of the variance was predicted by race, donor status, and side-effects. Caucasian race, living donor status, and more frequent side-effects each significantly contributed to the poorer parent perceptions of adolescent mental health. For adolescent reported mental health, 40% of the variance was accounted for by side-effects and family conflict, with more frequent side-effects and greater family conflict both significantly contributing to lower adolescent mental health outcomes.

Discussion

This study examined physical functioning and mental health of adolescent kidney, liver, and heart transplant patients. Although most domains of physical and psychosocial functioning were significantly correlated between parent and adolescent report, unique predictive models of physical and mental health functioning emerged for the parent and adolescent perspectives. Findings indicated that factors associated with the medical regimen, the level of family conflict, and aspects of the parents' quality of life predicted either the physical or psychological health for adolescent transplant recipients. From the parent and adolescent perspective, perceived medication side-effects emerged as a significant predictor of adolescent physical functioning and psychological well-being. The adverse side-effects associated with immunosuppressant therapy, steroids, and the other medications are extensive and well documented, including changes such as weight gain, changes in facial appearance, and decreased energy (23). In addition, adverse side-effects can decrease patients' likelihood of taking medication (12). This could fuel a vicious cycle wherein the physician may prescribe higher doses of medication to have the desired pharmacological effect, resulting in even more frequent and intense side-effects. The relationship between side-effects and medication taking also points to the importance of examining the direct relationship between non-adherence, and related consequences such as rejection, and health-related quality of life.

Family and parental physical functioning were also predictive of adolescent outcomes. This relationship is likely reciprocal with adolescents influenced by the context of the family, but also exerting influence on the family. Higher levels of family conflict were associated with poorer adolescent physical and mental health functioning, as perceived by the adolescent. This finding further supports the need for family-based interventions to assist adolescents with adjustment difficulties. Parents' own physical functioning was positively associated with adolescents' reports of their physical functioning. If their children are doing well, parents' physical health is also better. Conversely, poor physical functioning in the children may adversely influence their parents. In interacting with these parents at family camps and other settings, it is clear that much of their lives are dedicated to their child's healthcare. Some parents cope better than others with the challenges associated with their children's condition. It is important for healthcare

providers to address the needs of parents, as well as the children they care for.

Unique to the parent perspective, Caucasian race was a significant predictor of lower adolescent mental health. This finding may represent racial differences in responding to the CHQ and deems further investigation of the potential need to examine scores within and between racial groups. Interestingly, donor status also emerged as a predictor of parent perceived adolescent mental health. Parents of living donor recipients rated adolescents as having poorer mental health. We do not know how many of these parents were the actual donors for their child, but it is likely that this experience would contribute to parental perception of their child's emotional functioning. The experience of a living donor is important and is worthy of further research in understanding the quality of life of child recipients (24).

In addition to the findings described above, several other hypothesized results were found to be non-significant. Among these, age and socioeconomic level were not significantly associated with mental health outcomes. In previous research younger age was found to be a factor (8). It may be that given our restricted age range (11 yr and older), we did not have children who were young enough to detect this effect. Socioeconomic status also had been linked to anxiety in transplant patients (8) in prior research. Despite adequate variability, this relationship was not found in our sample. It may be that examining other factors that are often associated with socioeconomic status, such as extent of social support and a single parent home environment, would contribute to our understanding of mental health outcomes for adolescent transplant recipients. Several adolescent medical factors also were predicted to be associated with adolescent physical and mental health. However, perceived medication side-effects was the only variable to consistently emerge as an important predictor. Lastly, we examined several parent health-related quality of life variables. Among these factors, only parent physical functioning was important in understanding adolescent physical functioning.

There are several limitations in this study. This study is exploratory in nature. Several comparisons were made among variables increasing the chance of type I error. As research in this area is still limited, we desired to provide findings that will help guide hypotheses generation in subsequent research on health-related quality of life in adolescent solid organ transplant patients. Over half of the sample is composed of kidney patients; therefore the results of this study may

be more representative of this population than the other two organ groups. Importantly, however, the distribution across organ groups is representative of the proportions of solid organ transplants conducted in 2006, 66% kidney, 15% liver, 13% heart (2). The statistically non-significant differences found when comparing the three groups also suggest that these three groups are more similar than different and, therefore, depict a picture of the pediatric transplant community. It is important to note that although non-significant, parents of liver patients reported better physical functioning for their adolescent than the heart and kidney patients. This relationship should be explored further to determine whether in larger sample sizes there is a significant difference between liver patients and other transplant groups. We should also note that the findings in this study represent one transplant center and that results may be different at another site because of differing survival rates, medication side-effects, and demographic characteristics. A multi-site study of adolescent transplant recipients would afford the opportunity to examine the potential influence of site-specific influential factors.

Several future directions for research and clinical practice may be derived from the results of this study. The impact of medication side-effects on physical functioning and psychological well-being emphasizes the need for enhanced dialogue between adolescent transplant patients and their healthcare providers about medication side-effects and about possible plans for ameliorating their impact. While some side-effects may be unavoidable, recognizing their impact and providing additional support to these adolescents could serve as a protective factor against declining physical and emotional well-being. In addition, family conflict played a prominent role in adolescent physical and mental health. Fortunately, family distress and conflict are often amendable to family-based psychological interventions (25). Heightening awareness of the link between family conflict and adolescent physical and psychological functioning may lead to better screening and referral measures during outpatient follow-up. Finally, parents' physical functioning is also closely tied to the functioning of their children. Parents may be neglectful of their needs to fully serve as caretaker for their child. This can result in elevated psychological distress (26). However, parents' HRQOL is important in its own right, and parents who are functioning better are also better able to care for their children. These findings indicate that multiple factors influence adolescent health-related

quality of life. Taking a more comprehensive psychosocial approach may be warranted. Further development and inquiry into this approach is needed. As we continue to have better medical outcomes and longer graft life, treating the whole patient and the patient's family will be of greater importance.

References

- GUMMERT JF, IKONEN T, MORRIS RE. Newer immunosuppressive drugs: A review. *J Am Soc Nephrol* 1999; 10: 1366–1380.
- 2004 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1994–2003. Rockville, MD: Department of Health and Human Services Health Resources and Services Administration Healthcare Systems Bureau, Division of Transplantation; Richmond, VA: United Network for Organ Sharing; Ann Arbor, MI: University Renal Research and Education Association.
- GLAZER KM, EMERY CF, FRID DJ, BANYASZ RE. Psychological predictors of adherence and outcomes among patients in cardiac rehabilitation. *J Cardiopulm Rehabil* 2002; 22: 40–46.
- MEIJER SA, SINNEMA G, BIJSTRA JO, MELLENBERGH GJ, WOLTERS WH. Social functioning in children with a chronic illness. *J Child Psychol Psychiatry* 2000; 41: 309–317.
- BUCUVALAS JC, BRITTO M, KRUG S, et al. Health-related quality of life in pediatric liver transplant recipients: A single-center study. *Liver Transpl* 2003; 9: 62–71.
- WORLD HEALTH ORGANIZATION. World Health Organization constitution. In: *Basic Documents*, Geneva: World Health Organization; 1948.
- ALONSO EM, NEIGHBORS K, MATTSON C, et al. Functional outcomes of pediatric liver transplantation. *J Pediatr Gastroenterol Nutr* 2003; 37: 155–160.
- ENGLE D. Psychosocial aspects of the organ transplant experience: What has been established and what we need for the future. *J Clin Psychol* 2001; 57: 521–549.
- TORNQVIST J, VAN BROECK N, FINKENAUER C, et al. Long-term psychosocial adjustment following pediatric liver transplantation. *Pediatr Transplant* 1999; 3: 115–125.
- DIMATTEO MR, LEPPER HS, CROGHAN TW. Depression is a risk factor for noncompliance with medical treatment: Meta-analysis of the effects of anxiety and depression on patient adherence. *Arch Intern Med* 2000; 160: 2101–2107.
- KATON W, CIECHANOWSKI P. Impact of major depression on chronic medical illness. *J Psychosom Res* 2002; 53: 859–863.
- MEYERS KE, THOMSON PD, WEILAND H. Noncompliance in children and adolescents after renal transplantation. *Transplantation* 1996; 62: 186–189.
- DEW MA, KORMOS RL, DIMARTINI AF, et al. Prevalence and risk of depression and anxiety-related disorders during the first three years after heart transplantation. *Psychosomatics* 2001; 42: 300–313.
- BUCUVALAS JC, ALONSO E. Outcome after liver transplantation: More than just survival rates. *Liver Transpl* 2005; 11: 7–9.
- SIMONS L, BLOUNT RL. Identifying barriers to medication adherence in adolescent transplant recipients. *J Pediatr Psychol* 2007; 37: 831–844.
- ZELIKOVSKY N. Medication Adherence Measure (MAM). Unpublished Manual. Children's Hospital of Philadelphia; 2002.
- FRANKE GH, REIMER J, KOHNLE M, LUETKES P, MAEHNER N, HEEMANN U. Quality of life in end-stage renal disease patients after successful kidney transplantation: Development of the ESRD symptom checklist – Transplantation module. *Nephron* 1999; 83: 31–39.
- MOOS B, MOOS B. *The Family Environment Scale Manual*. Palo Alto: Consulting Psychologists Press, 1994.
- LANDGRAF J, ABETZ L, WARE J. *The CHQ User's Manual*. Boston: Health Act, 1999.
- SUDAN D, HORSLEN S, BOTHA J, et al. Quality of life after pediatric intestinal transplantation: The perception of pediatric recipients and their parents. *Am J Transplant* 2004; 4: 407–413.
- WARE J, KOSINSKI M, TURNER-BOWKER D, GANDEK B. *How to Score Version 2 of the SF-12 Health Survey*. Lincoln, RI: QualityMetric Incorporated, 2002.
- WARE J JR., KOSINSKI M, KELLER SD. A 12-Item Short-Form Health Survey: Construction of scales and preliminary tests of reliability and validity. *Med Care* 1996; 34: 220–233.
- CHISHOLM MA. Issues of adherence to immunosuppressant therapy after solid-organ transplantation. *Drugs* 2002; 62: 567–575.
- FORSBERG A, NILSSON M, KRANTZ M, OLAUSSON M. The essence of living parental liver donation—donors' lived experiences of donation to their children. *Pediatr Transplant* 2004; 8: 372–380.
- BAUMAN LJ, DROTAR D, LEVENTHAL JM, PERRIN EC, PLESS IB. A review of psychosocial interventions for children with chronic health conditions. *Pediatrics* 1997; 100: 244–251.
- SIMONS L, INGERSKI L, JANICKE D. Social support, coping, and psychological distress in mothers and fathers of pediatric transplant candidates. A pilot study. *Pediatr Transplant* 2007: OnlineEarly Articles.